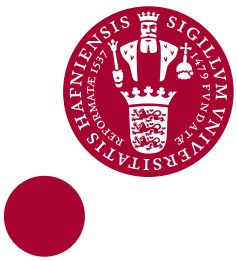

‘Getting to Zero’

The policy role of social determinants of health as they relate to children and youth living with HIV in sub-Saharan Africa

Belton, Sara; Skovdal, Morten

Published in:
Children and Youth Services Review

DOI:
10.1016/j.childyouth.2014.03.043

Publication date:
2014

Document version
Peer reviewed version

Children and Youth Services Review 45 (2014) 160–163

Contents lists available at ScienceDirect

Children and Youth Services Review

journal homepage: www.elsevier.com/locate/childyouth

'Getting to Zero': The policy role of social determinants of health as they relate to children and youth living with HIV in sub-Saharan Africa

Sara Belton [a,*], Morten Skovdal [b,c]

[a] Institute of Social Psychology, London School of Economics and Political Science, United Kingdom
[b] Department of Public Health, University of Copenhagen, Copenhagen, Denmark
[c] Save the Children, London, United Kingdom

ARTICLE INFO

Available online 4 April 2014

Keywords:
Policy
UNAIDS
Health services
HIV
AIDS
Children
Youth
Families

ABSTRACT

Major changes in UNAIDS international policy and treatment guidelines from 2010 to 11 still need to be correspondingly translated into policy and practice at national and local in-country levels. This special issue has drawn on social determinants of health (SDH) perspective to investigate how better to provide HIV and health services to affected children and youth. The articles featured here give examples of how a SDH perspective not only supports flexible and coordinated in-country service provision, but also fits well with UNAIDS' broader policy goals for the eradication of HIV and AIDS through the "Getting to Zero" policy campaign. We call for the widespread adoption of a SDH-based framework for policy, programming, and funding at all levels, to advance the UNAIDS policy goals of increased HIV service usage and decreased HIV rates in children and youth, as well as in all populations globally.

1. Introduction

1.1. Rationale for special issue

This special issue was developed from the conference "Growing up with HIV in Africa," held at the London School of Economics and Political Science, London, UK, in March, 2013, which brought together over 40 researchers and academics from 11 different countries who work in pediatric HIV/AIDS. The rationale for hosting this conference came out of research that suggests that children are a vastly underserved population affected by HIV/AIDS, despite pediatric medication being on the global market for over 20 years and increasingly available in most low-income countries (UNICEF, 2013). Whilst acknowledging that structural and materiel barriers are often the cause of such access problems (Barnett & Whiteside, 2006; Seeley et al., 2012), research also suggests that non-logistical barriers linked to the social landscape are also significant factors (Campbell, 2003; Campbell & Cornish, 2010), as access rates for children's HIV services are roughly half that of adults, not only in African countries, but globally (UNICEF, 2013). The conference and special issue therefore sought to examine the lived experiences of children and youth against current research and practices in the field, to take stock of where current practice is, and where it should be heading, to better serve children and their families and increase the uptake of HIV services overall. As the aim of current UNAIDS (2010) global policy is "Getting to Zero" in terms of new HIV infections, discrimination, and barriers to treatment, there are not only practice concerns to be considered, but policy implications as well.

1.2. Current state of global HIV/AIDS policy

In 2010, UNAIDS (2010) and WHO (2011a) announced new HIV/AIDS treatment guideline revisions, which called for the early introduction of anti-retroviral drugs (ART) in the treatment regime of people living with HIV, as recent research demonstrated improved day-to-day health and long-term survival rates with earlier initiation of drug treatment. Since then, HIV treatment guidelines and protocols continue to be further revised for adults and children, with a corresponding need to increase access and adherence to ART medication as outlined in the current "Treatment 2.0" initiative (WHO, 2013, 2011b). UNAIDS global policy was also changed (2010), with current policy for 2011–2015 advocating a massive scale-up of HIV testing and drug treatment, known as the "Getting to Zero" campaign. It can be considered the most ambitious policy response to the HIV/AIDS pandemic to date, as it calls for zero new HIV infections, zero AIDS-related deaths, achieved partly through an 80% ART coverage rate, and a commitment to work towards achieving zero rates of HIV-related discrimination (WHO, 2013, 2011b). Given these lofty goals, it has become clear that practice and policy will have to evolve, to facilitate such a massive response. UNAIDS argues that "Getting to Zero" will require a multifaceted approach, which inherently recognizes HIV as both a biomedical and a social disease, and which requires interventions at multiple levels with multiple stakeholders,

* Corresponding author at: Department of Social Psychology, London School of Economics and Political Science, WC2A 2AE London, United Kingdom.
E-mail address: s.k.belton@lse.ac.uk (S. Belton).

http://dx.doi.org/10.1016/j.childyouth.2014.03.043
0190-7409/

providers, and system users. Different ways of thinking and diverse perspectives would also help in achieving these goals.

However, despite UNAIDS advocacy for this shift in global policy and perspective, pre-existing policies and practices may undermine these goals, by creating or upholding significant barriers to their realization on the ground. Such problems include the continued duplication of services and programming across providers in a given location, due to vertical "silos" of program implementation and funding (Vassall, Remme, & Piot, 2012), instead of programming integration and coordination across service providers (UNICEF, 2013). Adding to this limiting environment are donor funding frameworks which encourage competition for exclusive grants and financing (Oomman, Bernstein, & Rosenzweig, 2007), as opposed to multi-sectoral funding consortia which can support a coordinated and integrated response across service providers in a given locality (OECD, 2008). Finally, a lack of mandate to meet local needs in terms of locally-appropriate flexibility in programming design, logistics, and technical capacity, also hampers efforts to implement the "Getting to Zero" policy (AVERT, 2014; Seckinelgin, 2012; UNICEF, 2013).

1.3. Implications of current global HIV/AIDS policy

Throughout this special issue, the contributors have explored how best to improve HIV services for children and youth, in order to increase the uptake of HIV services and improve the lives of young people infected by HIV. In doing so, we advocate for the adoption of a social determinants of health-based (SDH) perspective as a way of advancing the goals of the UNAIDS "Getting to Zero" policy campaign and translating it into measurable practice outcomes on the ground. As seen in the articles featured in this special issue and as discussed in Skovdal & Belton (2014), the SDH perspective can help practitioners develop and refine local programming to improve service delivery for children and their families, improving responsiveness and the ability to negotiate the complex biological and social components of HIV/AIDS across their lifespan. In addition, using a SDH perspective can bridge the gap between local programming realities and broader global policy goals, by intentionally bringing together biomedical and psycho-social components into one holistic perspective that recognizes the interdisciplinary needs of children infected with HIV.

SDH can trace its conceptual roots back to WHO's seminal public health conference at Alma-Ata (now Almaty) in 1978, where "Health for All" through the auspices of Primary Health Care was advanced as the best way to create healthy societies (WHO, 1978, 2009). It required a major conceptual shift towards broadening health indicators out from merely the biomedical and disease-linked, to include wider social-based factors (CSDH, 2008; Marmot, Rose, Shipley, & Hamilton, 1978), and has generated much interest and political controversy over the years (see for a review Labonte & Schrecker, 2007a,b). Although not without its critics, the policy ideals of Primary Health Care, Health for All, and SDH have been the theoretical backbone for much international health policy at the global level since the 1970s, and has been the theoretical basis for many national health systems and international health programs. Coming out of a UN-based institution, UNAIDS, the "Getting to Zero" campaign (2010) to reduce HIV/AIDS globally has SDH at its conceptual heart, as it balances the requirements of clinical disease management, with outlining the broader social changes needed to address the social factors which continue to fuel the pandemic, such as stigma, poverty, and gender inequality (Barnett & Whiteside, 2006; Campbell, 2003).

However, the SDH perspective has not been universally adopted in health systems around the world, which has resulted in many short sighted approaches when attempting to coordinate international policies with local practice realities. Since the Alma-Ata conference, there has been a varying acceptance of this conceptualization of health and health services, with some countries moving towards this framework and others not, resulting in very different health systems and system capacities and mandates, typically influenced by political, economic and social factors (Hall & Taylor, 2003; OECD, 2013a; Sachs, 2012). Yet, almost 40 years later, countries which have adopted a SDH theoretical perspective for their health and human services, in particular Canada and many nations in Europe, have obtained higher indicators of overall population health for less money spent on health, than those which have not adopted this conceptual framework, most notably the United States (OECD, 2013a,b). When balancing the high ideals of the UNAIDS "Getting to Zero" policy framework with the program-level realities of limited funding, personnel, and logistics, against the recognition that HIV/AIDS is a disease with both biomedical and psycho-social components, advancing this approach to policy and practice is all the more important.

2. Discussion

2.1. Advancing policy through a SDH perspective and model

Guided by a SDH perspective, we reviewed the articles included in this special issue and developed a SDH model as it relates to children and youth living with HIV in sub-Saharan Africa (Skovdal & Belton, 2014). We derived eight themes for service delivery which are key to supporting children and youth, as they manage the bio-psycho-social changes which occur as they grow up with HIV (Skovdal & Belton, 2014). These themes operate on both individual and social levels, and are: health services, family and kinship, poverty and economic resources, education and HIV awareness, social participation, healthy child development, community support structures, and culture and religion (Skovdal & Belton, 2014). Integrating the biomedical and social lived experiences of growing up with HIV into a holistic programming approach can help give structure to current UNAIDS policy directives, by giving practitioners a conceptual and contextual framework that reflects its multi-pronged approach. The papers presented in this special issue presented practical examples of applying a multi-pronged approach to service delivery.

Whilst current UNAIDS global policy as seen in "Getting to Zero" (2010) is comprehensive, "operationalizing" it locally is often challenging; however, policy is just an idea until it is put into action. Despite UNAIDS being the United Nations' lead organization on HIV/AIDS policy and programming coordination and advocacy, and therefore having a strong voice in terms of global leadership, this voice is at risk of being drowned out by other voices, particularly those of international donor countries, whose own perspectives, needs, and goals, are often very different from those of UNAIDS, WHO, and local HIV service providers (AVERT, 2014), and whose requirements and rules run the risk of taking precedence locally, as it is their financing which pays for the local programming, and "whoever has the gold makes the rules" (Oomman et al., 2007).

In this regard, UNAIDS, WHO, and recipient organizations and countries will have to group together and speak out against this misuse of power, and advocate for a change in mindset and practice from funders, so that local service providers can have the freedom and flexibility to respond to the local realities of their HIV pandemic as they see best. As "Getting to Zero" will ultimately require moving beyond a primarily biomedical treatment focus, using a more holistic, SDH-based perspective to effectively assess and target the local social conditions which continue to impede HIV prevention, care and support efforts, would be a better use of donor funds, and provide everyone with better long-term results. Further, creating and connecting practitioners in social networks which can share best practices across practice settings and realities, such as occurred with this conference and special issue, is another way of supporting this end.

2.2. Policy challenges to be addressed by social determinants of health model

Despite the many positive programming outcomes examined in this issue, there are still many policy challenges and hindrances which need to be addressed before the goals of "Getting to Zero" can be met to better

help children and youth living with HIV (UNAIDS, 2010; UNICEF, 2013). The main policy hindrances discussed in these articles reflect the wider global-local disconnect (Campbell, Cornish, & Skovdal, 2012) between international funders of HIV programming and local operators of services, whether Non-Governmental Organizations (NGOs), Faith-Based Organizations (FBOs), or Ministries of Health. Three main areas emerged as being particularly problematic for practitioners: that the current HIV/AIDS programming funding system encourages competition instead of cooperation particularly between service providers, that programming is adult-centric as opposed to being child- or family-friendly, and that monitoring and evaluation primarily serve the needs of international donors as opposed to local health providers and service users.

Regarding global funding structures currently in place, changes will be needed for "Getting to Zero" to become a reality. Despite years of debate on the nature and provision of international aid, current international funding for HIV/AIDS programming has two major flaws. First, current funding processes can fracture the capacity of local HIV/AIDS response, by creating competition between service providers which can result in the duplication or omission of services (Oomman et al., 2007), instead of cooperation between service providers and a coordinated, integrated, and multi-sectoral response (UNICEF, 2013), as also advocated by the Paris Declaration and Accra Agenda for Action (OECD, 2008). Examples where multi-sectoral approaches and better funding linkages could improve outcomes for children and youth living with HIV, include programs which would offset minor local access costs, such as to attend HIV programming (Mupambireyi et al. 2014; Schenk et al., 2014), or to increase uptake of HIV testing via incentives (Black et al., 2014).

Second, the "tied aid" style of funding, where donors dictate what programming the funding can be used for, can be too restrictive to effectively address the local needs of recipient countries, where the social factors which drive HIV infection may come into conflict with the differing ideals or expectations of the funding donor country (AVERT, 2014; Seckinelgin, 2012). Providing nutritional support to children on ART is vital to medical efficacy, yet this is not addressed in many treatment programs, thereby reducing drug efficacy and potential treatment outcomes (Sikstrom, 2014). HIV-positive children are also at risk for developmental difficulties, yet programming to support them and their families is still rare, as seen in Skeen et al. (2014) and Sherr et al. (2014). As such gaps have been identified using a SDH perspective, they can also be addressed using improved multi-sectoral funding approaches which reflect this perspective.

In addition, many articles presented in this issue have illustrated how children and youth with HIV have specific programming needs, which are best informed by their participation and feedback, given their own unique lived experiences, and the differing challenges faced in their life-long journey with HIV. Mattes (2014) reflects on ethnographic research with children to demonstrate how their unique needs are better served by child-centered programming, whilst Lowenthal et al. (2014) provide concrete examples from Botswana which reflect how such programming can be facilitated, with improved health outcomes for children and their families. Tailoring programming to the specific biosocial needs of children and youth, as opposed to simply "adding on" poorly modified adult programming, also helps to provide safe social spaces for children and youth to address more sensitive social issues and difficult conversations, such as their developing sexuality (Vujovic et al., 2014; Snyder et al., 2014), and the need for HIV-specific peer groups to assist in developing a positive social identity with others like themselves (Kajubi et al., 2014). Qualitative research which captures these unique perspectives and lived experiences, such as in Willis et al. (2014) and Fournier et al. (2014), can help program managers and policy makers alike to better understand, and correspondingly address these unmet needs and service gaps.

Finally, the current practices around the monitoring and evaluation (M & E) of HIV programming also need to be addressed. Whilst some international funders are responsive to local programming indicators and needs, others are less so and use indicators which suit the social realities of their home countries better than the countries which receive their grant money (Mannell, 2010; Vaughan, 2010). There is a need for a reconsideration of such practices, and a move towards M & E that strikes a better balance between local programming realities and needs, and the desires of international donors (OECD, 2008). M & E must "make sense" for local practitioners, and be able to better help them reflect on their local practice realities, and areas for improvement and change, as seen in Strasser and Gibbons (2014). M & E planning should also be reconfigured beyond simple election and grant cycles, to reflect the need for life-long, comprehensive programming which children and youth growing up with HIV will require (Sikstrom, 2014, Mburu et al., 2014), and which also reflects the wider programming realities of "Getting to Zero," where all HIV positive individuals who are started on ART will be on treatment for life.

3. Conclusion

3.1. Implications and ways forward

The articles included in this special issue have illustrated in various ways how there is a need to improve both policy and practice concerning children and youth living with HIV, if there is to be an increase in their uptake of HIV services. Whilst UNAIDS' "Getting to Zero" policy campaign has been revolutionary, it is only a starting point. Moving to an SDH-based approach to further programming and policy development would assist in improving HIV services for children and youth, particularly if combined with changes in funding approaches, a reorientation of programming to be more child- and youth-friendly, and a tailoring of monitoring and evaluation processes to help local staff better address the local challenges they face.

The ultimate goal of any policy should be to move forward an agenda for social changes necessary to help a society improve and advance itself in the face of its challenges. For children and youth living with HIV globally to have improved lives and health outcomes, there will need to be a better alignment of policy, practice, and the political. Practitioners, policy makers, politician, and HIV service users must come together to work together, in more open and egalitarian ways, in order to work towards achieving the shared goals of "Getting to Zero," with less competition and more collaboration. As a final example, this special issue and its related conference brought together over 40 academics and researchers working to improve HIV services for children and youth in 11 different countries. Such collaboration and networking is possible at any level. Broadening out perspectives to include the social determinants of health, improving funding processes, sharing best practices, and reorienting monitoring and evaluation to a better balance between global and local needs, will all help in "Getting to Zero."

Acknowledgments

Thank you to all the contributors of this Special Issue for their participation in the conference and preparation of manuscripts. Thanks also to the Annual Fund of the London School of Economics and Political Science for funding. Special thanks go to Imara Ajani Rolston and Rochelle Burgess for their editorial support of this Special Issue.

References

AVERT (2014). PEPFAR. Retrieved on 13 February, 2014, from: http://www.avert.org/pepfar.htm

Barnett, T., & Whiteside, A. (2006). *AIDS in the twenty-first century: Disease and globalization.* New York: Palgrave Macmillan.

Campbell, C. (2003). *Letting them die: Why HIV/AIDS prevention programmes fail.* Bloomington, IN: Indiana University Press.

Campbell, C., & Cornish, F. (2010). How can community health programmes build enabling environments for transformative communication?: Experiences from India and South Africa. *HCD Working Papers*, *1*. London, UK: London School of Economics

and Political Science (Retrieved 13 February 2014, from: http://eprints.lse.ac.uk/29002/).
Campbell, C., Cornish, F., & Skovdal, M. (2012). *Local pain, global prescriptions? Using scale to analyse the globalisation of the HIV/AIDS response.* (Retrieved 14 February, 2014).
CSDH (2008). Closing the gap in a generation: Health equity through action on the social determinants of health. *Final report of the commission on social determinants of health.* Geneva: World Health Organization (Retrieved 13 February 2014, from: http://whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf).
Hall, J., & Taylor, R. (2003). Health for all beyond 2000: The demise of the Alma-Ata Declaration and primary health care in developing countries. Retrieved 13 February 2013, from: https://www.mja.com.au/journal/2003/178/1/health-all-beyond-2000-demise-alma-ata-declaration-and-primary-health-care
Joint United Nations Programme on HIV/AIDS (UNAIDS) (2010). UNAIDS 2011–2015 strategy: Getting to zero. Retrieved 13 February 2014, from: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2034_UNAIDS_Strategy_en.pdf
Labonte, R., & Schrecker, T. (2007a). Globalization and social determinants of health: Introduction and methodological background (part 1 of 3). Retrieved 14 February 2014, from: http://www.biomedcentral.com/content/pdf/1744-8603-3-5.pdf
Labonte, R., & Schrecker, T. (2007b). Globalization and social determinants of health: Promoting health equity in global governance (part 3 of 3). Retrieved 14 February 2014, from: http://www.biomedcentral.com/content/pdf/1744-8603-3-7.pdf
Mannell, J. (2010). Gender mainstreaming in practice: Considerations for HIV/AIDS community organisations. *AIDS Care*, *22*(S2), 1613–1619.
Marmot, M., Rose, G., Shipley, M., & Hamilton, P. (1978). Employment grade and coronary heart disease in British civil servants. *Journal of Epidemiology and Community Health*, *32*, 244–249 (Retrieved 13 February 2014, from: http://jech.bmj.com/content/32/4/244.full.pdf+html).
OECD (2008). The Paris Declaration on Aid Effectiveness and the Accra Agenda for Action. Retrieved on 14 February 2014, from: http://www.oecd.org/development/effectiveness/34428351.pdf
OECD (2013a). *Health at a Glance 2013: OECD indicators.* OECD Publishing (Retrieved 13 February 2014, from: http://dx.doi.org/10.1787/health_glance-2013-en).
OECD (2013b). Country specific press release: USA. Retrievved 13 February 2014, from: http://www.oecd.org/unitedstates/Health-at-a-Glance-2013-Press-Release-USA.pdf
Oomman, N., Bernstein, M., & Rosenzweig, S. (2007). Following the funding for HIV/AIDS: A comparative analysis of the funding practices of PEPFAR, the Global Fund and World Bank MAP in Mozambique, Uganda and Zambia. Retrieved 13 February 2014, from: http://www.cgdev.org/sites/default/files/14569_file_FollowingFunding.pdf
Sachs, J. (2012). *The price of civilization: Reawakening virtue and prosperity after the economic fall.* London: Vintage.
Seckinelgin, H. (2012). The global governance of success in HIV/AIDS policy: Emergency action, everyday lives and Sen's capabilities. *Health & Place*, *18*(3), 453–460.
Seeley, J., Watts, C., Kippax, S., Russell, S., Heise, L., & Whiteside, A. (2012). Addressing the structural drivers of HIV: A luxury or necessity for programmes? Retrieved 13 February 2014, from: http://www.jiasociety.org/index.php/jias/article/view/17397
Skovdal, M., & Belton, S. (2014). *The social determinants of health as they relate to children and youth living with HIV in sub-Saharan Africa: Implications for service delivery.*
United Nations Children's Fund (UNICEF) (2013). Towards an AIDS-free generation — Children and AIDS: Sixth stocktaking report. Retrieved 14 February 14 2014, from: http://childrenandaids.org/files/str6_full_report_29-11-2013.pdf
Vassall, A., Remme, M., & Piot, P. (2012). World response to AIDS needs new vigour. Retrieved 14 February 2014, from: http://www.ft.com/cms/s/0/ac91eaae-3aff-11e2-bb32-00144feabdc0.html#axzz2tWHopLHl
Vaughan, C. (2010). When the road is full of potholes, I wonder why they are bringing condoms? The influence of local contexts on young Papua New Guineans' health and vulnerability to HIV. *AIDS Care*, *22*(S2), 1644–1651.
World Health Organization (1978). Declaration of Alma-Ata. Retrieved on 13 February 2014, from: http://www.who.int/publications/almaata_declaration_en.pdf?ua=1
World Health Organization (2009). Milestones in health promotion: Statements from global conferences. Retrieved on 13 February 2014, from: http://www.who.int/healthpromotion/Milestones_Health_Promotion_05022010.pdf
World Health Organization (2011a). Global HIV/AIDS response: Epidemic update and health sector progress towards universal access: Progress report 2011. Retrieved 13 February 2014, from: http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf
World Health Organization (2011b). The treatment 2.0 framework for action: Catalysing the next phase of treatment, care and support. Retrieved 03 March, 2014, from: http://whqlibdoc.who.int/publications/2011/9789241501934_eng.pdf
World Health Organization (2013). Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach, June 2013. Retrieved 13 February 2014, from: http://apps.who.int/iris/bitstream/10665/85321/1/9789241505727_eng.pdf